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Multiple Sclerosis Fatigue Management

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MULTIPLE SCLEROSIS FATIGUE MANAGEMENT MASTER'S PROJECT

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Introduction

Multiple Sclerosis (MS) is the most frequently diagnosed neurological disease causing disability in young adults. According to the National Multiple Sclerosis Society, MS affects approximately 400,000 individuals in the United States alone (Forwell, Copperman, & Hugos, 2008; National Multiple Sclerosis Society [NMSS], 2008). MS is an unpredictable disease and has varying effects on individuals, causing some individuals to become severely disabled, while others may show minimal effects and may lead active, productive lives (Forwell, Copperman, & Hugos, 2008; Mayo Clinic, 2006). In addition, the onset of MS may be subtle or may occur quickly and unexpectedly, with varying signs and symptoms (Calabresi, 2004; Mayo Clinic, 2006).

However, while symptoms may vary, MS fatigue is one of the most common symptoms, concerning more than 80% of individuals diagnosed with MS (Forwell, Copperman, & Hugos, 2008; National Multiple Sclerosis Society [NMSS], 2004). More specifically, MS fatigue is different from the type of fatigue that is experienced by the general population, as it usually occurs quickly and without warning, tends to be worse in the afternoon, and often occurs with exposure to warm temperatures. This fatigue can be overwhelming, result in limited energy, and can make simple tasks very difficult to complete. In addition, MS fatigue often interferes with daily activities such as work, recreation, and household management, thereby causing frustration and inhibiting an individual from participating in activities that are important, enjoyable, and meaningful (NMSS, 2004).

Furthermore, most individuals with MS are not well educated about and do not understand this complex symptom, thereby making it difficult to manage fatigue. These

individuals need to be informed that MS fatigue is a real symptom and is not a psychological problem, a sign of laziness, or associated with their motivational level. In addition, these individuals need to understand that they do not have to just accept living with fatigue and should be educated on and believe that they can make changes and learn new ways to effectively manage their fatigue to feel more energized and able to engage in important and meaningful daily life activities (NMSS, 2004).

Therefore, the purpose of this Master's Project was to research Multiple Sclerosis and to gather a significant amount of knowledge to thoroughly understand this disease and the effects it may have on an individual diagnosed with MS. More specifically and as previously stated, fatigue is a very common and often debilitating symptom of MS. As a result, this project was directed toward helping us, as students and future occupational therapists, to become fatigue management experts by learning how to intervene and teach fatigue management/energy conservation courses to a population of individuals largely impacted by this disease. In addition, it was our hope that through these courses we would be able to educate and assist individuals with MS on ways to take control and better manage their fatigue to live a more satisfying, functional, independent, and productive life.

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Understanding the Lived Experience of Multiple Sclerosis and Fatigue: A Literature Review

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Understanding the Lived Experience of Multiple Sclerosis and Fatigue: A Literature Review

Section One: Multiple Sclerosis

Introduction: What is multiple sclerosis?

Multiple Sclerosis (MS) is a chronic and potentially debilitating disease which affects the central nervous system (composed of the brain and spinal cord) (Mayo Clinic, 2006). MS is believed to be an autoimmune disease where "the body mistakenly directs antibodies and white blood cells against proteins in the myelin sheath, a fatty substance that insulates nerve fibers in the brain and spinal cord" (Mayo Clinic, 2006, p. 1). The sheath and nerves that it surrounds then become inflamed and damaged by the antibodies, resulting in multiple areas of scarring, known as sclerosis. This damage then slows or inhibits the nerve signals in the central nervous system, thereby affecting an individual's strength, muscle coordination, sensation and vision, often leading to varying degrees of impairment. An individual's signs and symptoms will ultimately vary depending on which nerve fibers are affected in the central nervous system (Mayo Clinic, 2006).

Prevalence and Incidence

Multiple Sclerosis (MS) is the most frequently diagnosed neurological disease causing disability in young adults and according to the National Multiple Sclerosis Society, MS affects approximately 400,000 individuals in the United States alone (Forwell, Copperman, & Hugos, 2008; National Multiple Sclerosis Society [NMSS], 2008). Individuals are usually diagnosed between 15 to 50 years of age (with the peak age being 20-30 years); however, children or late middle-aged adults may also be

diagnosed (Forwell, Copperman, & Hugos, 2008; Calabresi, 2004; NMSS, 2008). Women are also two to three times more likely to be diagnosed with MS than men and MS is the most common among Caucasians of northern European ancestry (NMSS, 2008; Calabresi, 2004; Forwell, Copperman, & Hugos, 2008).

Etiology

Although the specific cause is unknown, MS is more common in Europe, southern Canada, the northern United States, and southeastern Australia, all of which have temperate climates (Mayo Clinic, 2006). The incidence of MS also increases with greater distance from the equator (north and south) and the risk of MS is thought to be related to where an individual lives for the first 15 years of life (Forwell, Copperman, & Hugos, 2008). More specifically, it is believed that being farther from the equator, with decreased exposure to sunlight, results in low vitamin D and is a risk factor for MS (as vitamin D has been found to fight infections) (Challem, 2007). In a study by Munger, Levin, Hollis et al. (2006), researchers identified 257 MS cases in a United States military database of more than seven million people. They discovered that individuals with the highest blood levels of vitamin D were 62% less likely to have MS than were individuals with the lowest levels of vitamin D (as cited in Challem, 2007). In addition and as previously stated, while the cause of MS remains unclear, it appears that genetic factors/susceptibility may be involved even though the risk to first-degree relatives of individuals with MS (children, siblings) is less than five percent. Therefore, it is thought that the tendency to develop MS may be inherited and the disease becomes apparent after exposure to an infectious environmental trigger such as a virus, infection, or bacteria (Forwell, Copperman, & Hugos, 2008; NMSS, 2008; Mayo Clinic, 2006).

Furthermore, in a study by Ackerman et al. (2002), 85% of MS exacerbations were associated with one or more stressful life events from the previous six weeks. In addition, the study determined that a wide range of stressors with varying severities and from a variety of sources were equally linked to MS exacerbations. Therefore, it is believed that stressful life events may trigger MS disease activity (as stress affects the autoimmune system), leading to both the onset and development of MS and resulting in flare-ups/exacerbations for those already diagnosed with the disease (Ackerman et al., 2002).

Patterns of Multiple Sclerosis

The course of MS typically varies for each individual and there are four different types of MS including relapsing-remitting, secondary progressive, primary progressive, and progressive-relapsing. Most individuals with MS or approximately 80% are initially diagnosed with the relapsing-remitting type, experiencing flare-ups/exacerbations of symptoms followed by periods of remission or decreased symptoms. The flare-ups occur, usually last a few weeks or months, and then slowly disappear. More than half of individuals with relapsing-remitting MS then eventually experience a steady decline in health known as secondary progressive MS. Unanticipated relapses may also occur as the individual's health declines. Primary progressive MS is less common and occurs when individuals experience a continuous decline in health, without experiencing periods of remission. Finally, progressive-relapsing MS is characterized as primary progressive MS with sudden episodes of new symptoms or episodes where present symptoms become worse (Mayo Clinic, 2006; Forwell, Copperman, & Hugos, 2008; Noseworthy, Lucchinetti, Rodriguez, & Weinshenker, 2000). Benign and malignant MS are two other

terms used to describe MS where individuals experience minimal symptoms and are functional and healthy for a significant number of years after the onset of MS (benign) or experience rapidly progressing symptoms, quickly developing into significant disability or even death (malignant) (Forwell, Copperman, & Hugos, 2008).

Signs and Symptoms of Multiple Sclerosis

The onset of MS may be subtle or may occur quickly and unexpectedly, with varying signs and symptoms depending on which nerve fibers are affected (Calabresi, 2004; Mayo Clinic, 2006). "MS frequently is overlooked because initial symptoms resolve spontaneously in most patients" (Calabresi, 2004, p. 1935). Fatigue, one of the most common and debilitating symptoms of MS, affects up to 80% of individuals. Fatigue will be discussed in more detail in an upcoming section of this review (Forwell, Copperman, & Hugos, 2008). Additional MS symptoms may include: weakness or numbness in one or more limbs, monocular visual impairment with pain (optic neuritis), double vision or blurring of vision (diplopia), paresthesias (tingling or pain), Lhermitte's sign (electric shock sensations that occur down the spine during neck flexion), dizziness or vertigo, depression or emotional problems, urinary bladder, bowel, or sexual dysfunction, tremors, ataxia, lack of balance, coordination or unsteady gait, and sensitivity to warm temperatures, leading to increased fatigue. Individuals may also develop muscle stiffness or spasticity, dysarthria, dysphagia, or paralysis (Forwell, Copperman, & Hugos, 2008; Calabresi, 2004; Mayo Clinic, 2006; Noseworthy, Lucchinetti, Rodriguez, & Weinshenker, 2000; Finlayson, Garcia, & Cho, 2008). In addition, 40-60% of individuals with MS experience cognitive problems, which are seen at all stages of the disease, may be subtle, and are not directly related to motor

impairments. Common cognitive problems include difficulty with word retrieval, slowed information processing speed, difficulty learning new material, and problems with concentration, attention, memory, and executive functions (Forwell, Copperman, & Hugos, 2008; Mayo Clinic, 2006).

In order to treat and manage MS symptoms, a variety of medications are often used. Interferon-beta-1a (Avonex), Interferon-beta-1b (Betaseron), Glatiramer acetate (Copaxone), and Interferon-beta-1a (Rebif) have been shown to be effective by helping to regulate the immune system and slow the disease progression of MS. Mitoxantrone (Novantrone) is also used when the previously mentioned medications are no longer effective (Forwell, Copperman, & Hugos, 2008). In addition, there are several other medications that may be used to manage symptoms of MS. These include corticosteroids to decrease nerve tissue inflammation, amantadine (Symmetrel) and modafinil (Provigil) for fatigue, baclofen (Lioresal) and tizanidine (Zanaflex) for spasticity, numerous anti-depressants for depression, gabapentin for pain, and ditripan for urinary and bladder control problems (Forwell, Copperman, & Hugos, 2008; Mayo Clinic, 2006). Furthermore, a referral to a counselor, physical or occupational therapist may also be helpful to treat and manage the symptoms of MS (Mayo Clinic, 2006).

Multiple Sclerosis Effects on Activities of Daily Living

Multiple Sclerosis (MS) is an unpredictable disease and has varying effects on individuals, causing some individuals to become severely disabled, while others may show minimal effects and may lead active, productive lives. Therefore, early intervention is important to minimize and manage the effects of MS (Forwell, Copperman, & Hugos, 2008; Mayo Clinic, 2006). Lexell, Iwarsson, and Lexell (2006)

discussed a study completed by Mosley, Lee, Hughes, & Chatto (2003), stating that 78% of individuals with MS had difficulty with at least one occupation/activity, with the most frequently reported being mobility, work, community mobility, meal preparation and cleanup, dressing, talking, bathing, and grooming (Lexell, Iwarsson, & Lexell, 2006). Another survey by Finlayson, Winkler, Nicolle, & Edwards (1998) reported that out of 430 individuals with MS, yard work, employment, heavy housework, and going up and down the stairs were the most troubling occupations to complete (as cited in Lexell, Iwarsson, & Lexell, 2006). Similarly, according to a study completed by Finlayson, Garcia, & Cho (2008), the most common activities of daily living that were reported as always requiring assistance included using the stairs, ambulating inside the house, and stepping into and out of a shower or bathtub. Shoveling snow or doing yard work, doing heavy housework, and doing laundry were the most frequently reported instrumental activities of daily living that always required assistance (Finlayson, Garcia, & Cho, 2008). However, because most of the results from the literature are derived from combined scores from standardized assessments or questionnaires with predetermined choices, it is difficult to find detailed information regarding the specific occupations that individuals with MS identify as challenging to complete. There is also limited knowledge regarding the differences between gender, age, disease severity, and living arrangements in reported challenging occupations among individuals with MS (Lexell, Iwarsson, & Lexell, 2006).

To address this gap, Lexell, Iwarsson, & Lexell (2006) conducted a retrospective study with 47 individuals (28 women and 19 men) with MS. The study was designed to determine which daily occupations were difficult for individuals with MS to perform. The individuals were categorized using the Expanded Disability Status Scale (EDSS) as

either having mild, moderate, or severe MS and also completed the Canadian Occupational Performance Measure (COPM). With the COPM, each individual reported the daily occupations that were difficult to perform, then rated the importance of each occupation on a scale of 1 (not important) to 10 (most important), and finally the most important occupations were prioritized and rated according to the individual's perceived performance and satisfaction on a scale of 1 (not able to do/not satisfied) to 10 (able to do extremely well/extremely satisfied) (Lexell, Iwarsson, & Lexell, 2006).

The 47 individuals reported a total of 366 occupations that they felt were difficult to engage in. The highest number was reported in the area of self-care (51%), followed by productivity (30%), and leisure (19%). In addition, the subcategories household management (26%), personal care (21%), and functional mobility (20%) accounted for two-thirds of the occupations that were reported as challenging to complete. The individuals then prioritized 238 occupations and among those, functional mobility and paid/unpaid work were rated as the most important, while quiet recreation was rated the least important (Lexell, Iwarsson, & Lexell, 2006).

Furthermore, the average performance and satisfaction ratings were both generally low for these prioritized occupations, thereby affecting an individual's ability to continue engaging in these activities. In regard to paid/unpaid work, it is not uncommon for an individual to be unemployed due to the symptoms, unpredictability, and progression of MS. In addition, while leisure activities (socialization, active recreation) received high ratings of importance for individuals with MS, the performance and satisfaction ratings were also low (Lexell, Iwarsson, & Lexell, 2006). According to a study by Hakim et al. (2000), only 3% of individuals with severe MS continued to spend

time with friends and participated in social activities outside of the home (as cited in Lexell, Iwarsson, & Lexell, 2006). Therefore, as can be seen from the variety of results, "individuals with MS perceive difficulties with a variety of occupations related to all aspects of daily life" (Lexell, Iwarsson, & Lexell, 2006, p. 247).

The studies above examined specific activity areas that individuals with MS have difficulty completing. However, as can be seen and described, MS also affects an individual's overall quality of life. To understand this more concretely, Forbes, While, Mathes, & Griffiths (2006), studied the relationship between problems faced by individuals with MS and their health-related quality of life. Quality of life was measured using the SF-36 which provides a subjective measure of an individual's health status across eight different scales: physical functioning, social functioning, role limitations due to physical problems, role limitations due to emotional problems, mental health, energy/vitality, bodily pain and general health perception. The results illustrated that individuals with MS scored lower on all of the scales in comparison to the data collected from the general population. Also, as the severity of problems experienced by individuals with MS increased, the scale scores from the SF-36 decreased more significantly, once again indicating a reduction in quality of life (Forbes, While, Mathes, & Griffiths, 2006).

In addition, Matuska & Erickson (2008) carried out a phenomenological study to determine how MS affects an individual's ability to have a balanced life. As a result, five different themes were identified as challenges faced when living with the disease, thereby affecting an individual's participation in activities of daily living and leading to an unbalanced lifestyle. More specifically, due to the unknown and unique nature of MS,

individuals often experience multiple symptoms and therefore must manage their basic health needs and stress, frequently requiring lifestyle changes to stay healthy. The individual's social participation, interaction with others, as well as the ability to carry out numerous roles and responsibilities may be affected due to fatigue and limited energy. In addition, due to the debilitating effects of MS, many individuals are forced to modify or eliminate many of the activities that they previously engaged in, must find meaning in alternative occupations/activities, and must strive to establish a positive identity that is not associated with MS. Furthermore, due to fatigue, individuals often prioritize the day to ensure that the most important activities are completed, then allowing little time or energy for more challenging and engaging activities. As a result, individuals with MS must be flexible and willing to make adaptations in their daily lives in order to overcome the aforementioned challenges to be able to live a meaningful, balanced, and productive life (Matuska & Erickson, 2008).

Multiple Sclerosis Fatigue

Fatigue is one of the most common symptoms associated with MS, affecting up to 80% of individuals (Forwell, Copperman, & Hugos, 2008; Schreurs, de Ridder, & Bensing, 2002; Vanage, Gilbertson, & Mathiowetz, 2003). In addition, 50-60% of individuals describe fatigue as their most disabling symptom (Holberg & Finlayson, 2007). Whether physical fatigue or cognitive/mental fatigue, it has been shown that fatigue worsens, even after only one year, significantly affecting one's activity level (Schreurs, de Ridder, & Bensing, 2002). According to Krupp, Alvarez, LaRocca, & Scheinberg (1988), as cited in Vanage, Gilbertson, & Mathiowetz (2003), fatigue affects each individual differently, often interfering negatively with daily functioning and overall

occupational performance. Krupp et al. (1988) also reported on the difference in fatigue experienced by individuals with MS compared to healthy individuals, discovering that MS fatigue often prevents and interferes with sustained physical activity, becomes worse with warm temperatures, comes on easily, interferes with fulfilling obligations, and leads to repeated problems in daily life (as cited in Vanage, Gilbertson, & Mathiowetz, 2003). One individual described MS fatigue as feeling "just like the plug being pulled in the bathtub and all the water going down" with this feeling occurring all of sudden and without any warning (Stuifbergen & Roger (1997) as cited in a review article by Smith & Hale, 2007, p. 49).

Causes of Multiple Sclerosis Fatigue

With MS, there are both primary and secondary causes of fatigue. Primary MS fatigue is thought to occur as a result of the MS disease process and the cause is not well understood while secondary MS fatigue occurs from different conditions/disease-related factors that increase primary fatigue (Forwell, Copperman, & Hugos, 2008; Matuska, Mathiowetz, & Finlayson, 2007; National Multiple Sclerosis Society [NMSS], 2004). In a program manual created by The National Multiple Sclerosis Society titled *Fatigue: Take Control*, eight secondary causes of fatigue are identified. These include: heat sensitivity, weakness, depression, poor nutrition, sleep disturbances (due to bladder issues, pain, spasticity), inactivity/deconditioning, medication side effects, and other medical issues/conditions such as infections or illnesses (NMSS, 2004).

Fatigue Management

In order to treat and manage primary MS fatigue, which occurs as a result of the disease process, the two most frequently prescribed medications include modafinil (Provigil) and amantadine (Symmetrel) (NMSS, 2004). Both of these medications are stimulants and appear to be effective in reducing fatigue (Mayo Clinic, 2006). In addition, the secondary causes of fatigue can be controlled by changing medications, going to counseling or taking medication for depression, and using cooling techniques or avoiding warm environments to decrease body temperature. Improving one's nutritional intake, developing appropriate and structured exercise routines, receiving treatment for weakness and sleeping problems, and using energy conservation techniques can also be used to decrease and manage secondary MS fatigue (NMSS, 2004).

Furthermore, appropriate exercise programs and energy conservation courses are often used to manage secondary MS fatigue. Regular aerobic exercise programs should be created and individualized to each participant. Individuals should also be educated on the difference between exercising to increase endurance and exercising during daily functional activities. However, while exercise is important, it is necessary to know one's limits and to create an appropriate exercise program in order to ensure that one's daily functioning is not negatively affected (Forwell, Copperman, & Hugos, 2008). In addition, energy conservation courses focus on teaching strategies to enable individuals with MS to "use their limited energy on useful, meaningful activities that are important to them. This approach allows the client to exercise choice and control in everyday occupations" (Forwell, Copperman, & Hugos, 2008, p. 1088). By analyzing activities and daily schedules, understanding the importance of rest breaks between activities, developing appropriate exercise routines, and identifying how to modify tasks, the environment, and

use appropriate equipment, individuals should become more familiar with the ways to conserve energy and manage MS fatigue in order to live a more productive life (Forwell, Copperman, & Hugos, 2008).

More specifically, in 1995, occupational therapists Packer, Brink, and Sauriol created a course titled *Managing Fatigue: A Six-Week Course for Energy Conservation* which was intended for individuals experiencing fatigue as a result of a chronic illness (Vanage, Gilbertson, & Mathiowetz, 2003). The course

> does not aim to correct the underlying mechanisms that cause fatigue, nor does it accept that the solution is to decrease activity levels or reduce the breadth and extent of activities. Rather it promotes a positive attitude aimed at active decision-making and optimum use of available energy to fit the unique needs of each individual (direct quote from Packer, Brink, & Sauriol (1995), as cited in Mathiowetz, Matuska, & Murphy, 2001, p. 450).

The course principles are focused on the importance of rest, planning and storing energy, taking rest breaks, communicating with others, using good posture and body mechanics, using energy-saving appliances, and adapting the environment. In addition, the course focuses on the importance of breaking activities into parts, prioritizing and setting standards with activities, planning rest breaks during daily activities to maintain a healthy balance, and setting short and long-term goals (Vanage, Gilbertson, & Mathiowetz, 2003; Matuska, Mathiowetz, & Finlayson, 2007; Mathiowetz, Matuska, & Murphy, 2001; Mathiowetz, Finlayson, Matuska, Chen, & Luo, 2005).

Research on the Effectiveness of Fatigue Management Strategies

A study completed by McCullagh, Fitzgerald, Murphy, & Cooke (2008), demonstrated the positive effects of exercise on managing fatigue. 24 individuals with either relapsing-remitting or secondary progressive MS participated in the study (with 12 in the exercise group and 12 in the control group). Individuals in the exercise group

attended exercise classes two times per week for 12 weeks and also exercised independently at home one time per week. As a result, after three months, individuals in the exercise group showed significant improvements in fatigue, quality of life, and exercise capacity as demonstrated by results from the Modified Fatigue Impact Scale (MFIS), Multiple Sclerosis Impact Scale-29 (MSIS-29), Functional Assessment of Multiple Sclerosis (FAMS), Heart rate (HR), and the Borg's Rating of Perceived Exertion (RPE) Scale. These improvements were also maintained after six months, with the exception of exercise capacity (McCullagh, Fitzgerald, Murphy, & Cooke, 2008). However, as previously stated, while these results support the use of exercise to manage fatigue, it is also important to discuss the use of exercise with a doctor or trained health care professional before beginning or modifying a program to identify any precautions, limitations, and to ensure that the exercise program is appropriate and will not lead to an increase in MS symptoms or exacerbations (Forwell, Copperman, & Hugos, 2008).

Several different studies have also evaluated the effectiveness of the energy conservation course, also looking at whether or not the energy conservation principles were used and which principles were used most frequently by individuals with MS. In 2001, Mathiowetz, Matuska, & Murphy completed a study to determine if the 6-week energy conservation course (originally developed by Packer et al.) would have an effect on fatigue impact, self-efficacy, quality of life, and behavior change (whether or not participants would actually use the fatigue management/energy conservation strategies and continue to use them over time). After the 19 week study involving 54 individuals, the results showed a significant decrease in fatigue impact on all three subscales (cognitive, physical, and social), it showed a significant increase in participant's self-

efficacy, and a significant increase on three quality of life (QOL) subscales (vitality, social functioning, and mental health) for those who participated in the energy conservation course. The results also showed no significant difference in fatigue impact, self-efficacy, or QOL before and after the support group sessions (the control) or during the last six weeks of the study (the no treatment period), demonstrating that the effects of the course were maintained for several weeks (Mathiowetz, Matuska, & Murphy, 2001). Additionally, the study revealed that after participating in the energy conservation course, 82% of the individuals used six or more energy conservation strategies and 35% used ten or more in their daily life, reporting that their use of the strategies increased after the course (Mathiowetz, Matuska, & Murphy, 2001).

Similarly, in a quasi-experimental study of individuals with progressive MS, completed by Vanage, Gilbertson, & Mathiowetz (2003), a significant difference was found. Scores from the Fatigue Impact Scale (FIS) for individuals who participated and completed the energy conservation course decreased, demonstrating a reduction in fatigue impact while FIS scores from individuals who did not attend the energy conservation course changed only slightly. This decrease occurred with each of the FIS subscales (cognitive, physical, and psychosocial) and with the total FIS scores. In addition, not only were the FIS scores lower after attending the energy conservation course, but this decrease was maintained for at least eight weeks (Vanage, Gilbertson, & Mathiowetz, 2003). Then, in 2005, Mathiowetz, Finlayson, Matuska, Chen, & Luo conducted a large randomized controlled trial with 169 individuals with MS, randomly assigning individuals to the immediate intervention group (to participate in the energy conservation course first) or to the delayed control group (to participate in the energy

conservation course six weeks later). Significant differences were found among all three analyses between the two groups with decreases noted in the physical and social subscales of the Fatigue Impact Scale (FIS) for those participating in the energy conservation course. The vitality subscale of the SF-36 (measuring quality of life) was also significant among all three analyses, demonstrating an increase in quality of life after participating in the course. In addition, significant differences were found in regard to self-efficacy with carrying out energy conservation techniques, with self-efficacy scores being significantly greater after the course than before the course, demonstrating that individuals were more confident, motivated, and willing to use the techniques (using an average of 9.2 new energy conservation techniques) (Mathiowetz, Finlayson, Matuska, Chen, & Luo, 2005).

Mathiowetz, Matuska, Finlayson, Luo, & Chen (2007) then completed a one-year follow-up to the previous randomized controlled study, determining that overall the results were maintained. Significant decreases in fatigue impact and significant increases in some of the quality of life subscales were found, thus further emphasizing the long-term effectiveness of the energy conservation course for individuals with MS (Mathiowetz, Matuska, Finlayson, Luo, & Chen, 2007).

Health Education and Multiple Sclerosis

Because of the unique nature of MS and the variety of effects this disease can have on one's health, education is essential to help individuals understand the disease process to be able to function as independently as possible for as long as possible. In an exploratory study completed by Finlayson in 2004, using a phenomenological approach with in-depth interviews, participants articulated numerous concerns about the future

when living with MS. These included a fear of losing one's mobility and independence, a fear of becoming a burden to others (family, friends, caregivers) by requiring extra assistance, and a fear of having to move into a nursing home resulting in the feeling of a loss of independence and control. In addition, these fears were linked to the individual's knowledge and education regarding MS and its unpredictability, their personal observations and insights into the physical changes they were experiencing, and their knowledge that aging often results in additional physical changes that may affect their current health (Finlayson, 2004).

Therefore, as a result, Finlayson (2004) concluded that it would be beneficial to provide education that focuses on reorganizing one's life and planning for the future, while developing strategies to manage and gain control over one's activities and surroundings. In addition, by working together with families as well as with social workers, psychologists, and other health care professionals to understand and address proper care-giving, this may alleviate one's concerns about becoming a burden to others. Furthermore, to decrease the need for nursing home care, unless legitimately necessary, educating individuals with MS and their families on healthy occupations, home modifications, and assistive/adaptive technology could improve housing and community care options and better the lives of those in need (Finlayson, 2004).

How to be an Effective Educator

However, while health education is important for individuals living with MS, in order to be effective and have an influence on those in need, it is necessary to focus on and understand what factors influence individuals and lead to behavior change. In a study by Matuska, Mathiowetz, & Finlayson (2007), it was determined that in order for

health education to be effective, specifically relating to managing fatigue through energy conservation techniques, it is necessary to focus on more than just presenting the information and the information should be delivered "using methods that compel behavior change, at times when people are most receptive to change and in ways that increase confidence in their ability to change" (Matuska, Mathiowetz, & Finlayson, 2007, p. 63). By keeping this in mind, the chances of creating change should increase and individuals will benefit more from the education they are receiving.

Similarly, in an article by Lerman & Glanz (1997), as cited in Mathiowetz, Matuska, & Murphy (2001), the use of active learning activities during educational courses were thought to improve each participants' self-efficacy or confidence in one's abilities. By improving one's confidence, this has shown to have an influence on whether or not various health behaviors are adopted (Mathiowetz, Matuska, & Murphy, 2001). Moreover, in a review article by Nieuwenhuijsen, Zemper, Miner, & Epstein (2006), looking at health behavior change models and theories, it has been determined that before an individual participates in any type of health action or behavior change, the individual must first have the intention to participate. In addition and as previously mentioned, "self-efficacy, not just 'know how,' proves to be the essential factor leading to the monitoring and regulation of one's health actions within the contextual environment" (Nieuwenhuijsen, Zemper, Miner, & Epstein, 2006, p. 251). Therefore, by remembering this and focusing on one's confidence and inner beliefs, while educating and working with individuals with MS, the likelihood of cooperation, participation, and future success should be increased.

Additional Factors Influencing Participation in Fatigue Management Techniques

Holberg & Finlayson (2007) completed a study specifically looking at which factors influence whether or not individuals with MS will use energy conservation techniques to manage their fatigue. These researchers used the Transtheoretical Model of Change as the framework to guide the study. More specifically, this model focuses on intentional change that occurs over time as individuals try to create behavior change and the decisions that one must make when moving through the stages of pre-contemplation, contemplation, preparation, action, and maintenance (Cancer Prevention Research, 1998 and Prochaska et al., 1994 as cited in Holberg & Finlayson, 2007). In addition, although MS-related fatigue is a symptom of MS and not a behavioral problem, the Transtheoretical Model can still be applied since behavioral change is needed in order to accept and adopt the strategies needed to adequately manage MS fatigue (Holberg & Finlayson, 2007).

As a result, after individuals participated in the energy conservation course by Packer et. al (1995), completed an extensive semi-structured open-ended interview, and a Stage of Change Questionnaire, four major themes were identified. The first three included *Experience with the Disease, Sense of Self*, and *Environmental Factors*, all of which addressed the factors that increased and decreased the use of energy conservation/fatigue management strategies. The fourth theme identified was the *Value of Education* and described how participating in the energy conservation course helped individuals learn to better manage their lives with MS and influenced their willingness to adopt the recommended strategies/techniques (Holberg & Finlayson, 2007).

To further describe the previously mentioned themes and the factors included in each theme, *Experience with the Disease* encompassed the individual's level of disability,

fatigue experiences, and extent of MS disease progression, all of which impacted the strategies used and how they were used. As can be expected, individuals with significant disability and impairments often experienced more difficulty and were less likely to implement the strategies. *Sense of Self* included the individual's view of him/herself as a person with MS and whether or not the individual had accepted MS while *Environmental Factors* included the individual's physical surroundings (availability of adapted equipment, access to rest areas) and level of social support received from others. Once again, as can be expected, individuals with a strong sense of self, as well as adequate physical and social support tended to implement more strategies. The fourth theme, the *Value of Education,* described how the energy conservation course helped to change participants' perspectives on fatigue (shifting the guilt from being tired and weak away from the individual and toward the disease), increased their willingness to implement strategies, and increased their awareness of effective and ineffective strategies to gain better control over their fatigue (Holberg & Finlayson, 2007).

Therefore, by identifying these factors, health educators should be more aware of and be able to recognize what issues may be affecting an individual's participation and engagement in fatigue management strategies. Then, with this knowledge, the educator should be able to make appropriate changes and adaptations to ensure that the educational sessions are consistently productive and effective for everyone involved.

Section Two: In-depth Interviewing

Description: What is an in-depth interview?

In-depth interviews are usually carried out with one individual, during a face-to-face verbal interaction between the interviewer and interviewee, but can also be carried out over the telephone or in a group (Kielhofner, 2006; Robson, 2002; Fontana & Frey, 1998). More specifically, in-depth interviews can be carried out in several different ways and may be structured, semi-structured, or unstructured (Kielhofner, 2006).

With structured interviews, the design and order of questions are controlled. Interviewers ask each question exactly how they are written and the questions may either lead to a fixed or open-ended response (Kielhofner, 2006). Structured interviews allow for limited flexibility, as the questions and response categories are generally predetermined and the interview protocol is set and should be followed by asking the same questions in the same order and in the same way (Kielhofner, 2006; Robson, 2002; Fontana & Frey, 1998). This type of interview may be used with telephone or face-to-face interviews, as well as with interviews related to survey research. In addition, while structured interviews lead to the least amount of in-depth information, these interviews are generally more straightforward and standardized (Fontana & Frey, 1998).

With semi-structured interviews, there is increased flexibility throughout the interview and both fixed-response and open-ended questions are used (Kielhofner, 2006; Robson, 2002). In addition, semi-structured interviews have predetermined questions, but the order and wording of the questions can be altered, explanations can be provided, and questions can be added or omitted based on the responses of each interviewee. A semi-structured interview usually includes a list of topic headings with key questions under each heading. The interviewer begins with a topic and is directed by the

interviewee's responses to determine which topics and which questions to discuss next (Robson, 2002).

Unstructured interviews allow for the largest amount of flexibility and are often similar to a guided or informal conversation. A list of questions (an interview guide) is used and the interviewee has the freedom to respond in his/her own way (Kielhofner, 2006; Robson, 2002). The interviewer respects the interviewee's responses but when appropriate, may probe and ask follow-up questions to further explore and expand on the interviewee's initial responses to gather more in-depth information. Probing is meant to encourage the interviewee to share more specific information, to provide examples and offer explanations, and is not meant to direct or sway the interview in any particular way (Kielhofner, 2006; Robson, 2002). Most importantly, unstructured interviews convey "the attitude that the participant's views are valuable and useful, and the task of the researcher is to capture these views as completely and accurately as possible" (Kielhofner, 2006, p. 345).

In addition and as previously stated, with in-depth interviews (more specifically semi-structured and unstructured interviews), the interviewer may modify the questions that are asked depending on the interviewee's response and the information obtained. However, to allow this flexibility while also keeping some structure to the interview, in-depth interviews are generally composed of three types of questions: main questions, probes, and follow-up questions. Main questions are used to begin and guide the interview, probes are used to clarify or ask for further information or examples, and follow-up questions are used to further explore main themes and allow the interviewee to expand on previous answers and ideas (Rubin & Rubin, 1995).

Lastly, semi-structured and unstructured interviews are frequently used in qualitative research designs and are often referred to as qualitative research interviews (Robson, 2002). These interviews are recorded with audiotapes, written notes by the interviewer, and video recorders occasionally may be used. This provides permanent documentation of the interview, allows the interviewer to concentrate on the interview, ensures that sufficient information is obtained from the interview for future analyses, and verifies that the information obtained is accurate (Kielhofner, 2006; Robson, 2002).

Purpose of an In-depth Interview

The purpose of an in-depth interview is to explore and examine a specific situation, perspective, experience, or issue. More specifically, the interviewer listens and tries to explore and understand the thoughts, ideas, and experiences of the interviewee in order to gather the most detailed and in-depth information about the issue/topic being discussed (Kielhofner, 2006; Rubin & Rubin, 1995). The goal is to understand specific circumstances experienced by individuals and to better understand how and why things happen (Rubin & Rubin, 1995; Fontana & Frey, 1998).

Strengths of Interviewing

There are several advantages to using in-depth interviews. First of all, these interviews can result in a large amount of detailed information. When comfort, respect, trust, and confidentiality have been established between the interviewer and interviewee, the interviewee is usually more willing to share personal information (in comparison to sharing in a large group with several other individuals) (Kielhofner, 2006). Additional topics can also be discussed based on the interviewee's responses to previous questions due to the flexibility of this type of interview (Kielhofner, 2006; Robson, 2002).

Furthermore, non-verbal cues can be observed during the interview, setting the tone and providing additional information to help understand the interviewee's responses (Robson, 2002; Fontana & Frey, 1998).

Limitations of Interviewing

On the contrary, there are several limitations to using in-depth interviews. First of all, the interviewer may lack the skills and training needed to develop appropriate and effective questions and may not know or feel comfortable with probing and asking follow-up questions, which are essential during the interview. In addition, interviewees may not feel comfortable sharing personal information or may not discuss experiences that are significant or pertinent to what is being studied. Information obtained from interviews is self-reported and often subjective, as interviewees express their personal thoughts, experiences, and perspectives. While most of the time this is acceptable, if more objective data is needed, other methods of data collection may need to be used (Kielhofner, 2006). More specifically, interviews are generally not standardized, which decreases the reliability of the data obtained and may result in biased information (Robson, 2002).

Another limitation with interviewing is the amount of time needed to complete this task. Interviews require adequate preparation (establishing questions, making and confirming arrangements to meet, receiving consent from the interviewee, rescheduling appointments if necessary) and require time after the interview to write notes, transcribe tapes, and analyze the data (Robson, 2002). Data and information obtained from the interview requires a significant amount of time to analyze and can be costly to transcribe (Kielhofner, 2006). In addition, in-depth interviews lack efficiency as it takes

significantly more time to interview one individual than it does to interview a group of individuals (Kielhofner, 2006; Robson, 2002).

How to be an Effective Interviewer

In order to be effective when interviewing, the interviewer should present him/herself as competent and skilled (Kielhofner, 2006). This should occur through practice and receiving feedback from others (Robson, 2002). The interviewer should be confident, open-minded, flexible, and ready to change the direction of the interview depending on the individual's response (Rubin & Rubin, 1995). If specific words or phrases are not understood during the interview, it is important for the interviewer to ask for clarification in order to increase understanding (Rubin & Rubin, 1995; Fontana & Frey, 1998). Interviewers also need to prepare for a wide range of situations/circumstances/experiences when planning and participating in an interview in order to be appropriately prepared for challenges that may arise (Kielhofner, 2006).

In addition, it is important for the interviewer to develop strong listening skills, to demonstrate the ability to interact with others, to know how to structure questions, and to know when/how to probe for increased explanations (Kielhofner, 2006). It is important to listen more than to speak, to frame questions in a clear and non-threatening way, to remove cues which may influence how an interviewee responds, and to act as though the interview is enjoyable by using appropriate intonation and facial expressions (Robson, 2002). An interviewer's personal feelings, assumptions, biases, and beliefs can easily influence the questions that are asked, how they are asked, and the interpretations that are made. Therefore, it is important for the interviewer to be aware of this in order to keep the line of communication open and to increase the interviewee's comfort level during

the interview (Rubin & Rubin, 1995). "Qualitative interviewing requires intense listening, a respect for and curiosity about what people say, and a systematic effort to really hear and understand what people tell you" (Rubin & Rubin, 1995, p. 17). More specifically, interviews require cooperation, as well as trust and rapport among the interviewer/interviewee (Kielhofner, 2006; Fontana & Frey, 1998). The interviewer must be able to put him/herself in the place of the interviewee and must try to view the situation/circumstance from the interviewee's perspective (Fontana & Frey, 1998). As stated by Fontana & Frey (1998), "to learn about people we must remember to treat them as people, and they will uncover their lives to us" (p. 73).

Importance of Interviewing and Understanding the Lived Experience of Multiple Sclerosis Fatigue

Overall, it is important to take the time to interview, listen, and try to understand the effects of MS and the lived experience of fatigue, as fatigue is one of the most prevalent symptoms experienced by individuals with MS and can often have debilitating effects on one's daily life (Forwell, Copperman, & Hugos, 2008). By understanding this experience, one should be able to relate to future clients and be more effective in treating individuals with MS who experience fatigue daily. In addition, by taking the initiative to understand, one should be able to gain trust and build a strong relationship with individuals living with MS, as well as gain empathy and compassion for those affected by this disease.

Section Three: Importance of Multiple Sclerosis Fatigue Management Master's Project Discussion:

As can be seen, MS is a very complicated disease and can lead to a wide variety of symptoms, affecting each individual differently. While the specific cause of this disease is still unknown, the prevalence and incidence of MS is significant, especially in temperate climates such as the northern United States (Mayo Clinic, 2006). As a result, it is necessary to continue to provide both pharmaceutical and non-pharmaceutical interventions (i.e. fatigue management/energy conservation courses) to those in need. In addition, this literature review confirms that these courses *are* being used and have been effective with managing fatigue and positively influencing individuals with MS. Therefore, in order to continue to decrease the impact of MS on daily life, individuals need to be educated and supported throughout the disease process.

Furthermore, future research studies could look at the following questions to continue to improve and positively influence future management of this disease. First of all, would it be valuable to include family members and employers in the fatigue management/energy conservation course to increase their understanding of the disease (Matuska, Mathiowetz, & Finlayson, 2007)? Would the fatigue management/energy conservation course be as effective in an inpatient rehabilitation program or could the course be completed online? Does the fatigue management/energy conservation course actually affect an individual's physiological measure of fatigue just as it affects the individual's self-report of fatigue? Are there specific types of individuals that would benefit from the course more than others or are there certain characteristics of individuals that might help to predict whether or not the course would be useful? For example, is there a specific level or type of cognitive deficit that might inhibit an individual from learning during the course? This would then provide health care professionals with more

information when deciding whether or not to recommend the course to individuals with MS. Finally, would this course be effective for individuals experiencing fatigue as a result of other chronic diseases (Mathiowetz, Finlayson, Matuska, Chen, & Luo, 2005; Mathiowetz, Matuska, Finlayson, Luo, & Chen, 2007)?

Conclusion and Purpose of Master's Project

Overall, the purpose of this Master's Project was to research Multiple Sclerosis as a whole in order to gather a significant amount of knowledge to thoroughly understand this disease and the effects it may have on an individual diagnosed with MS. More specifically, as can be seen, fatigue is a very common and often debilitating symptom of MS. Therefore, this project was directed toward helping us, as students and future occupational therapists, to become fatigue management experts by learning how to intervene and teach fatigue management/energy conservation courses to a population of individuals largely impacted by this disease. In addition, it was our hope that through these courses we would be able to assist individuals with MS to better manage their fatigue to become more functional, independent, and productive throughout daily life. Furthermore, an in-depth interview and focus group were completed with the individuals participating in the fatigue management course to further understand MS fatigue and its impact on daily life, as well as to identify common themes among each individuals' unique fatigue experiences.

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Project Description

Program description

Fatigue: Take Control is a six week course developed by a team of interdisciplinary individuals from the National Multiple Sclerosis Society who specialize in Multiple Sclerosis (MS). The course is designed to teach individuals diagnosed with MS about their fatigue and how to manage this symptom, as fatigue is common and often debilitating for those living with this disease. *Fatigue: Take Control* focuses on the most important aspects of MS fatigue through videos, group discussions, goal setting, and workbook/homework activities. More specifically, the six different sessions focus on the medical management of fatigue, how to make pro-active energy choices, the importance of adding exercise into daily life, how to modify the environment, how to make changes and choices to take control of fatigue, and a summary and overview of the previous topics. Each session of the course is approximately two hours in length and is intended to help individuals learn how to make the necessary changes in their activities, behaviors, and environments and how to take the steps needed to manage their fatigue (National Multiple Sclerosis Society [NMSS], 2004).

Training

In regard to the training for the fatigue management course, our master's project class met in a classroom setting where our instructors, Kathleen Matuska and Barbara Gilbertson, provided us with the leader and participant manuals for the course, explained each session agenda, discussed the required materials, and gave us the opportunity to view the videos, read the course content for each session, and ask questions. We then practiced each session in class with our group members (watched the videos a second

time, talked about possible discussion questions), decided on the amount of time we wanted to spend on each activity, and discussed who would be responsible for each part of the session. Individual preparation was also necessary to ensure that the information for each session was understood and could be effectively delivered to the participants in the course.

Individual Role in Fatigue Management Course

During the fatigue management course, I was responsible for preparing and teaching sessions one, two, four, and five, taking more of a leadership role during sessions two and five. More specifically, Krystle Maloney and I taught sessions one and four while Christine Loos and I taught sessions two and five. Teaching each session included bringing the group together by making everyone feel welcome and comfortable, explaining each session's objectives, showing videos, reviewing the previous week's workbook/homework assignments, leading small and large group discussions, offering question and answer periods, explaining the following week's workbook/homework assignments, and providing closure to the session. During the other two sessions when I was not teaching, I acted as a facilitator to assist my group members (Krystle and Christine) when necessary and helped out wherever possible to ensure the sessions went smoothly. I also volunteered to take responsibility for making copies and organizing all of the materials (manuals, handouts, evaluations) needed for each weekly course session.

Participant Descriptions

A total of eight individuals (six women, two men) participated in the fatigue management course throughout the seven offered sessions; however, an average of 5-6 individuals were in each weekly session. Several participant photographs were taken

throughout the course after receiving written permission from each individual (see Appendix). The participants were very interactive, talkative, and open with each other, and appeared to be comfortable with everyone in the group, often joking around with one another and emphasizing their want and desire to stay together each week. All of the individuals were in wheelchairs, with seven of them in power wheelchairs and one of them in a manual wheelchair. Cognitive deficits were apparent in more than half of the group members, with individuals having difficulty with executive functions (problem solving, paying attention, initiating and completing activities, etc.), with remembering and recalling information, and with finding the right words to use when speaking. In addition, as could be expected, when looking at the entire group of participants, the level of acceptance of MS appeared to be related to experience with the disease, as those who were diagnosed many years ago seemed to be at a later stage in the acceptance/coping process in comparison to the individuals diagnosed more recently. The following are brief descriptions of each individual participant in the fatigue management course.

Participant 1: Participant one is a 45-year-old woman who was diagnosed with MS eight years ago. Her MS has become increasingly worse within the last two years. She is unable to walk and just switched from using a manual wheelchair to using a power wheelchair. She is able to use her upper extremities, but has difficulty writing due to numbness and tingling in her fingers. She currently works four hours/week, lives alone, and receives help from personal care assistants and her parents. Participant one enjoys scrap booking in her free time. She also appeared to be at an earlier stage in the grieving/acceptance process as she stated that she has difficulty letting things go, saying "no", and making changes due to the MS. Participant one was not able to attend every

session due to therapy and pre-planned appointments, but she appeared to benefit from the course information.

Participant 2: Participant two is a 61-year-old woman who was diagnosed with MS 30 years ago. She is unable to walk and uses a power wheelchair. She is able to use her upper extremities and currently works one day/week as a registered nurse doing chart reviews. She was married but divorced after 40 years, lives alone, and receives help from personal care assistants. She also thoroughly enjoys cooking and baking. Participant two was very open to sharing her experiences and appeared to accept/cope with MS rather well, but also expressed her frustrations frequently. She reported that she went to counseling to help with this. She also appeared to know where changes should be made in her lifestyle due to the MS, but due to her high level of motivation she reported that she doesn't always follow through with the changes.

Participant 3: Participant three is a 44-year-old man who was diagnosed with MS nine years ago. He is currently unable to walk and uses a power wheelchair. He reported that he hasn't been on his feet for several months. He is able to write and use his upper extremities and currently does not work. He is married, receives help from his wife, and enjoys playing computer games and watching Stock Car racing. Participant three was very open and willing to share his experiences and appeared to be at a similar level of acceptance/coping as participant two, but was rather laid back.

Participant 4: Participant four is a 49-year-old man who was diagnosed with MS nine years ago. He is somewhat able to walk and uses a power wheelchair. He reported that walking is painful. He is able to write and use his upper extremities and currently does not work. He lives alone and does not receive help from anyone. He also enjoys playing

card games. During one session he expressed that he has a lot of pride and doesn't like to ask for help. Participant four liked to make jokes and sarcastic comments. He missed several of the beginning sessions of the course and upon his return, he reported that he had experienced a bad exacerbation where most of his body went numb.

Participant 5: Participant five is a 60-year-old woman who was diagnosed with MS 11 years ago. She is unable to walk and uses a power wheelchair. She is married and receives a significant amount of help from her husband, stating that she feels very blessed. Participant five was rather quiet and was unable to attend several sessions, but stated that she enjoyed the course sessions, enjoyed listening to others, and found the information being presented very helpful.

Participant 6: Participant six is a 44-year-old woman who was diagnosed with MS 21 years ago. She is able to walk and uses a manual wheelchair. She is also able to write and use her upper extremities and she works three hours/week. She is married and has an 11 year old daughter, both of whom help her at home. She also enjoys attending her daughter's cheerleading competitions. Participant six was willing to share her experiences, appeared very interested in the course material, but appeared to have more observable cognitive deficits (difficulty with memory, understanding, etc.) and some difficulty with articulation when speaking.

Participant 7: Participant seven is a 54-year-old woman who was diagnosed with MS 30 years ago. She is able to walk short distances (due to fatigue) and uses a power wheelchair. She is able to write and use her upper extremities and currently does not work. She lives alone and does not receive help from anyone on a daily basis. Participant seven was very open and willing to share her experiences and was very

interested in others' experiences. She reported that she is very into exercise and being active, and she played numerous sports (i.e. softball) before being diagnosed with MS. She also demonstrated several cognitive deficits (difficulty with memory, judgment, etc.) and stated that she often has difficulty with cognition and has been diagnosed with organic brain dysfunction.

Participant 8: Participant eight is a 62-year-old woman who was diagnosed with MS 35 years ago. She is unable to walk and uses a power wheelchair. She has very minimal use of her right upper extremity due to weakness and has normal function in her left, but is unable to write. She also has difficulty with articulation when speaking. She currently does not work, lives alone, and receives help from personal care assistants. Participant eight was willing to share her experiences and appeared to be interested in the fatigue management information. She also reported that she really enjoys swimming and the way it makes her body feel, but is unable to currently engage in this activity due to a broken leg.

Table 1

Participant Demographics

Gender	Age	Time of Diagnosis [a]
F	45	8
F	61	30
M	44	9
M	49	9
F	60	11
F	44	21
F	54	30
F	62	35

Note. F= female; M= male. [a] Time of diagnosis is reported as X years ago.

Location and Time of Fatigue Management Course

The fatigue management course was held at the Fairview Multiple Sclerosis Achievement Center (MSAC) on University Avenue in St. Paul, Minnesota. This center provides special programs for individuals with progressive MS to slow the disease progression, to address each individual's physical, emotional, and spiritual needs, and to help the individuals remain active and independent for as long as possible. Individuals can receive rehabilitation services (occupational, physical, speech, and recreational therapy), attend educational programs (i.e. fatigue management courses), social activities, and receive moral support from staff and others living with the disease. Social workers and chaplains are also on staff at the center to provide support and resources to the individuals with MS, their families, and their caregivers (Fairview Health Services, 2007).

In addition, the course was held every Thursday morning from 10:30-12:30 pm, for seven weeks (January 15th- February 26th). The first weekly session was dedicated to the focus group and the other six sessions were dedicated to the fatigue management course.

Participant Recruitment Process

The individuals who participated in the fatigue management course were specifically chosen by the staff at the Multiple Sclerosis Achievement Center. The staff looked at the different days of the week and which members visit the center regularly to determine who would benefit the most from the fatigue management course. The staff presumed that individuals with significant cognitive deficits, as a result of the MS, would most likely find it challenging to receive and process the information being presented. Therefore, they focused on recruiting individuals with higher cognitive levels who would

be able to learn new information and carry forward what they learned to use during practical situations. They also focused on recruiting individuals who live in family homes or assisted living facilities and are able to be more independent and structure their own time (in contrast to individuals living in group homes which are much more structured). In addition, Thursdays were chosen for the fatigue management course, as this day of the week had previously had the best participant attendance. When the individuals were asked what they wanted to receive from the MS Achievement Center, the Thursday group expressed the most interest in receiving outside education (i.e. our fatigue management course). All of the individuals were approached and given an option on whether or not they wanted to participate in the course and everyone agreed; no one turned it down. The staff at the MS Achievement Center then assigned the individuals to each group.

Participant Attendance Patterns

On average, there were 5-6 individuals participating in the fatigue management course each week. Compared to the other two groups of participants, we had a small group. However, the individuals appeared to appreciate this set-up as it gave us the opportunity to attend to the participants on a more individual basis and allowed them to ask more questions and contribute more fully to the discussions. Individual participants also arrived late, left and returned during the session, or left early based on therapy sessions or pre-planned appointments. As a result, the flow of each session and the participants' attention and focus were affected. However, we tried to be flexible and effectively adapt to these interruptions by bringing the group back together to keep the

course running smoothly and to ensure that we had enough time to cover all of the information and complete all of the activities during the designated time.

Focus Group or In-depth Interview

Individual assignment

For this portion of the MS Fatigue Management Master's Project I was responsible for carrying out an in-depth interview with one of the individuals from our fatigue management course. In order to be the most accommodating to the individual participating, I was flexible in regard to the time and place of the interview. I also asked the individual if she was comfortable being recorded during the interview and upon agreement, she signed a form to document her written consent (see Appendix). The interview was carried out for approximately two hours in her home environment.

In addition, interview questions were developed prior to the interview by our master's project class and were used to act as a guide during the interview (see Appendix). The interview was a combination of a semi-structured and unstructured interview and was intended to gather qualitative data through the individual's rich and detailed responses. The main research question was to determine how MS and fatigue has impacted the individual's daily life. A few of the other questions included: "Describe your fatigue", "How have your roles/routines/relationships/daily activities been impacted by fatigue", and "At this point, what do you do to try to manage your fatigue?" The interview also allowed the individual to describe her personal MS story more completely and gave me the opportunity to listen and better understand the lived experience of this disease.

Interview Recruitment Process

At the end of the second session of the fatigue management course, I made an announcement to all of the individuals in the session, asking if anyone would be interested in being interviewed. I explained that the questions would be similar to the questions used during the focus group, but that it would be a one-on-one interview which would allow for a more in-depth discussion, talking specifically about the individual's unique MS story and experiences. Two individuals volunteered and then decided amongst themselves who would participate in the interview. Once this was decided, I pulled the individual aside and talked to her to set up the date, time, and place for the interview and we exchanged phone numbers in the event that further communication or re-scheduling was necessary.

Interview Transcript Analysis: How This Was Completed

After I completed the in-depth interview using a recorder to tape the qualitative data, I transcribed the two hour interview word-for-word using my computer and an audio program (see Appendix). This process took approximately 10-12 hours to complete. I then analyzed the transcribed interview by individually coding it line-by-line, underlining key words and phrases, while also interpreting what I thought the interviewee was saying and feeling throughout her responses. I made notes in the margins of the page using short phrases and descriptive words. I then met with my professor, Barbara Gilbertson, who had also read and coded my interview, and we discussed what we had each found by comparing and contrasting our results. We then tried to identify several main themes that were common and evident throughout the interviewee's responses. This process required us to look at the data repeatedly and very carefully, going back and

forth between the identified themes and key words and phrases. As a large group we then discussed our results, identified similarities and differences between the various participant interviews, and tried to assist one another with narrowing down the themes even more. I then met with my professor one last time and we agreed upon three main themes that were the most prominent throughout the interview, with several sub-themes falling under each main theme.

References

Fairview Health Services. (2007). *Fairview multiple sclerosis achievement center*. Retrieved January 24, 2009, from http://www.fairview.org/rehab/Services/

National Multiple Sclerosis Society [NMSS]. (2004). *Fatigue: Take control.* New York: National Multiple Sclerosis Society.

Results-Recommendations

Fatigue: Take Control

Personal lessons learned about teaching

After teaching the fatigue management course, I learned a significant amount about myself. While I have always been an organized, conscientious, and hard-working individual who is interested in helping others, I realized that I am quite comfortable working with this population and am very interested in learning about multiple sclerosis and how it affects each individual differently. I also learned that I enjoy teaching others, facilitating a group, and taking an active leadership role. I become energized by being around people and have a strong desire to ask questions, provide knowledge, and be an effective educator.

In addition, I have realized that while I tend to get nervous and talk fast at the beginning, this feeling usually subsides rather quickly during the session and I am able to relax and feel comfortable. I also like to follow a schedule and appreciate the feeling of being completely prepared, but have realized that sometimes this is not always realistic and it is important to be flexible and prepared for the unexpected.

Furthermore, while I generally do not have difficulty being a leader and taking an active role, I have come to realize that I do not always demonstrate or feel confident in my ability to do so. I have also realized that I occasionally have difficulty and need to further develop my skills when moderating a group of individuals. I find it challenging to know when and how to appropriately facilitate participation, yet also interrupt individuals during an off-task discussion or activity, as I do not want to be disrespectful or offend anyone. As a result, this periodically affects my ability to be in control and causes me to

hesitate more than I should. More specifically, I have learned that I need to improve on knowing when and how to appropriately and confidently react to participant responses and actions in order to increase my effectiveness when teaching and leading a group.

I have also realized that I appreciate constructive feedback and am able and very willing to adapt my behaviors and actions if I am provided with proper feedback (see Appendix for instructor and peer feedback forms). I have realized that I am a hard-working and motivated individual who is prepared and eager to make the necessary changes in order to improve my skills and abilities.

Lessons Learned About Teaching Effectiveness

When looking at what it takes to be an effective teacher/educator, I learned that it takes a significant amount of time, patience, and experience to develop these skills. First of all, I learned how important it is to be prepared, organized, confident, and ready to provide knowledge on the designated topic. This confirms to the participants that the educator is interested and serious about the content being taught. However, as an educator, I have also realized that you can only be so prepared and that it is extremely important to be flexible, as each course session may vary based on participant needs, the amount of discussion elicited, and whether or not assignments are completed.

Learning how to effectively moderate or create a flow to the course session, using active listening, and knowing when and how to appropriately and confidently react to participant responses and actions (to minimize feelings of disrespect or disregard) can be a challenge, as it is important to allow the participants to have some control, while also keeping the session on track. Allowing the discussion to stray for a short amount of time and then politely interrupting to bring the group back or tying the conversation into the

topic being discussed was generally effective, but not always easy. However, our ability to moderate the group and create a flow to each session improved as time went on.

In addition, I learned that it takes time to develop a rapport and really get to know the members, but that the more comfortable the participants are with the educators, the more likely they are to participate in the group. It is also important to frame the discussion questions in a way that facilitates conversation and everyone should be encouraged to participate to create a unified environment where all members feel a part of the group. Moreover, as an educator, it is important to find ways to motivate individuals to apply the knowledge that is learned and actually make changes. Throughout this course it was helpful to have the participants talk to each other and use one another as a resource to determine what is effective in regard to specific fatigue management techniques. Due to the fact that many of the participants have lived with MS for several years, they are the experts on the disease and are more likely to listen to others faced with similar circumstances than to listen to an outside resource who has limited knowledge and personal experience with the disease.

Furthermore, I believe the participants appreciated and learned a significant amount from the course. They seemed receptive to the information, continued to attend and participate, were willing to learn, and appeared to appreciate and find the information being presented very beneficial. Several of them stated that they have become more aware of their daily patterns and have started to make lifestyle changes to be more energy efficient and to decrease their fatigue levels. Most of the individuals also brought back their three-ring binders each week to collect the new weekly session manuals and many

of them completed the homework assignments/activities each week (either by writing down their responses or taking the time to think about their responses).

Overall, not only did we learn a significant amount from each participant, but the participants were also able to teach one another. In addition, I believe we were able to provide them with the necessary information and encouragement and what they decide to do with it depends on each individual's situation. A seed has been planted and it is our hope that over time, it begins to grow and lead to positive changes in each and every one of our participants.

Need for Adaptation

In order to be an effective educator, I believe every course should be adapted to meet the needs of the participants. As a result, due to the number of individuals with varying degrees of MS, it was necessary to make several adaptations during the fatigue management course. First of all, because all of the individuals were in wheelchairs, we set up the tables appropriately so there was adequate room and everyone could fit comfortably, yet still be able to see the other participants, their course materials, and the videos being presented. When the participants had difficulty with upper extremity functioning, we provided assistance to complete the session evaluations and manipulate the course handouts.

Most of the individuals also demonstrated some sort of cognitive deficit as a result of the MS; therefore, we often used simpler terms, provided explanations, clarified, or repeated the information. It was also not uncommon for the group to get off track during discussions or lose focus of the topic of conversation, so after letting the conversation stray for a short amount of time, we tried to politely interrupt to bring the

group back or tried to tie in the conversation to the topic being discussed. This was sometimes difficult, but was usually a very effective approach. As a result, we also had to adapt the time allotted for each of the discussions and activities based on the level of participation, the number and depth of responses, and whether or not the group stayed on task.

Furthermore, due to therapy sessions and pre-planned appointments, it was not uncommon for the participants to arrive late, leave for part of the session, or leave early. Therefore, at times there were only a few individuals in the room, which affected the dynamic and depth of the discussions, but also gave us the opportunity to speak with the individuals on a more personal level. In addition, for those who missed part of the session, we tried to quickly play "catch up" and often spoke to the individuals separately to explain any missed information. We also tried to be flexible when there were distractions due to individuals coming and going during the session. When this occurred, we tried to minimize the interruptions, keep the session moving, and quickly bring the participants back to the designated activity.

As previously discussed, we provided manuals and handouts during each session of the course. In the beginning, while the participants appeared somewhat overwhelmed by the wealth of information provided in the manuals, we decided to continue providing the packets of information, but asked the participants each week if they wanted the new material. We decided that the manuals were very informative and could be read at a later time or shared with family members, friends, or personal care assistants interested in learning more about MS and fatigue. As the weeks went on, the participants appeared to enjoy and appreciate receiving the new material. We also provided each participant with

a three-ring binder at the beginning of the course to hold all of the materials. The participants were asked to bring the binders back each week to collect the next session's manual and handouts. However, anticipating that the participants would occasionally forget to return the binders, we 3-hole punched and paper-clipped all of the materials so that the information would stay together and could be added to the binder at a later time. We also kept the materials for each session in a large file box and provided the manuals/handouts to individuals who missed sessions but still wanted the information.

Each session of the course also included "homework" assignments for the participants to complete and return the following week. When we initially explained this, many of the individuals appeared overwhelmed and displeased with this request. Therefore, while we never intended to sound as though the assignments *had* to be completed, we immediately informed the participants that while we encouraged them to complete the activities, this was not absolutely necessary and it would be valuable to just think about the activities. Despite this, many of the participants actually completed the activities each week. However, to accommodate to those who had difficulty writing or preferred not to complete the assignments, we either spent time doing them during the session (depending on the activity and the number of individuals in the group) or we allowed a few minutes during the session to think about the assignment before discussing it as a large group.

Overall and most importantly, we tried to be flexible, prepared for the unexpected (as much as possible), and tried to attend to each individual's differences. We also helped out when needed, tried to facilitate discussion among all group members, and provided encouragement to everyone involved. Each participant had so much to offer

throughout the course and each individual's unique stories and experiences were invaluable to everyone in the group.

Program Evaluation Results

Overall, the weekly course evaluations revealed positive results. Completing an evaluation after each session, 94-100 % of the participants were satisfied and felt that the course objectives were met each session. Most of the participant evaluations also confirmed that the program activities were useful. More specifically, the participants found the questions and group discussions to be helpful, especially when discussing strategies and ideas that have been effective for managing fatigue and conserving energy. The participants also found it especially beneficial to look at the different types and levels of fatigue, to learn how to bank their energy and balance activities with rest, to learn the difference between exercise and daily functional activity, and to break down and analyze activities to see if changes need to be made to better conserve their energy. Staying on task during discussions and already having knowledge of various session topics were comments made regarding what was least helpful or could be changed to improve the course.

Furthermore, the last session of the course was dedicated to reviewing the main objectives of fatigue management. While playing a game, the participants were asked a variety of questions, most of which they answered correctly. They also accurately discussed several different concepts and pieces of course information, demonstrating that they understood and had acquired a significant amount of knowledge during the past seven weeks regarding energy conservation and fatigue management techniques. At the end of the program, the participants also informed us that they enjoyed and appreciated

the course and felt that we effectively taught and presented the information. They liked the format of the course, thought that we asked good questions, and reported that the most beneficial aspects of participating in the course were the presenters, the quality of the course material, the other course participants, and being able to apply the information to real-life, practical situations.

In-depth Interview

Results of analysis: Themes of meaning

A modified phenomenological study was completed as I carried out an in-depth interview with one of the participants from our fatigue management course. For the purpose of this paper, I will use the name "Karen" as a pseudonym when describing the participant.

After transcribing and thoroughly analyzing the interview through the previously described process, several different themes were identified. More specifically, based on Karen's responses, it was interpreted that she feels overwhelmed and as though the MS has taken control of her life, that because of the MS she has experienced a change in her routines and roles as a daughter, friend, and member of society, and that life with MS is complicated and has required her to make numerous modifications and adaptations.

Due to the uncertainty and unpredictability of the MS disease process, it is not uncommon for an individual to feel a loss of control. However, with Karen's case, while she was diagnosed approximately eight years ago, her MS has become increasingly worse within the last two years as she has experienced numerous exacerbations within a short period of time (4 relapses in 6 months). According to the doctor, her MS has changed from the relapsing-remitting type to aggressive secondary progressive. In other words,

this already chronic disease is progressing very quickly, leading to an increase in debilitating symptoms. As Karen stated, "I'd go in each month with a whole list of new things that were going on." Some of these symptoms included limping, severe depression, foot drop, blindness, facial droop, numb fingertips, a hoarse voice, and extreme fatigue. She was also experiencing a significant number of falls as evidenced by her response:

> When I got to his office and he took a look at me, I was black and blue from the waist down. And we're not talking just a little blue, we're talking massive, looked like someone had beaten me up with a baseball bat. I was falling by that time, 15 times a day.

As a result, it appears as though the MS has completely taken control and Karen is caught in the middle of this whirlwind of changes.

MS fatigue is a significant reason why Karen feels a lack of control in her life. Due to the extreme nature of this symptom, it is difficult for her to predict when and where she is going to fall asleep. During the interview Karen described her fatigue by stating:

> I have absolutely no control over how or when I'm gonna go to sleep. When it comes, it comes and it hits me like a baseball bat. You know it just hits and it comes and it'll come so rapidly that I don't even know it's coming. I mean, as I said, I could be sitting here, feeling just great like I am now, talking to you, and all of a sudden bammo I'm asleep.

She also discussed how it makes her feel, knowing that she can fall asleep so quickly and without any warning. Not only is this scary and frustrating, but it also makes Karen feel very vulnerable when she is out in public or with unfamiliar individuals. She stated:

> It's very intense and it's very frightening for the people that have witnessed it. It makes me very angry, it embarrasses me. I think another thing that it does is that it scares me, because I never know where I'm going to be when I'm gonna fall asleep.

This extreme and sudden onset then makes it difficult for her to engage in simple daily tasks and often has a negative impact on her ability to participate in meaningful and enjoyable activities. When discussing the effects of her fatigue, Karen stated:

> I really want to watch a TV program, but I've never been able to watch the end of a TV program when I turn it on at night. I'll watch the TV program and I'll know that it's about oh, quarter after or maybe even twenty-to and I'll wake up and it will be five or 10 minutes after I've wanted to watch the end of my program and it frustrates me.

In addition, Karen demonstrated that this lack of control and decreased participation, as a result of the fatigue, significantly impacts the way she feels and affects the way she communicates her needs to others. In her opinion, even though she knows how extreme her fatigue is, she believes that staying awake should not be a difficult task. Karen stated:

> I deny that I'm tired which I don't want people to know that I'm tired because it, I don't know why but, it embarrasses me…I don't want to admit to people that I'm getting tired or maybe I don't want to admit to myself that I'm tired. I guess maybe that's what it is. I don't want to admit to myself that I'm so fatigued that I can't make it through the day without a couple of naps…So yeah, it's embarrassing but I get angry at myself that I can't do it. Why can't you do this Karen? Why can't you do a simple thing like stay awake?

Karen also expressed why she doesn't like to tell others that she is tired. She stated:

> I don't want to admit it. I want to be a normal person and that's, I know that's not right saying that, because I am a normal person, but I don't feel like a normal person because normal people don't fall asleep four or five times during the day.

Finally, I think one of the last comments that Karen shared with me during the interview summarizes the wide variety of emotions she feels as a result of the MS and not being able to feel in control of her life due to all of the sudden and overwhelming changes. She stated:

> I just looked at everybody and I said, I'm depressed as hell, I'm scared to death, I don't want to die, nobody told me about MS when I started, nobody told me what

> I was going to get into, nobody told me how bad it was going to be, nobody told me how hard it is, I don't know where to go, I don't know what to do.

This statement was made during one of her previous support group meetings at the MS Achievement Center.

The second theme that emerged from Karen's responses during the interview was her change in routines and roles as a daughter, friend, and member of society as a result of the MS and fatigue. Karen described how at one point along her journey with MS, not only was she forced to quit working, but her daily routine also became much more simple. She stated:

> I had to quit work because of fatigue because I was so tired. It's like I'd wake up at 8 in the morning, get dressed, shower, whatever, do my hair, eat breakfast, hour later I was ready to go back to bed again. And I did sometimes, just went back to bed and slept for a couple of hours and then I'd get up and eat lunch, fall asleep again. That's all I was doing was waking up and falling asleep. I didn't do anything. I mean my life was nothing at that time but sleeping and getting up and sleeping and getting up.

Karen also discussed her loss of daily structure and how the MS has taken control of her life. Due to the sudden progression of the disease and her limited knowledge and ability to effectively manage all of the changes, the MS has placed several limitations on her routines. She explained this well when she stated:

> It was actually I think June of last year when things were getting really bad physically for me with my MS and things were getting really depressing for me and I wasn't really able to do much. My life consisted of doctor's appointments or sitting at home watching TV or staring at the wall or something.

However, not only have Karen's routines been changed, but her role as a daughter and her parents' roles have also been transformed throughout the MS disease process. Karen has become more dependent on her parents as she requires more support and

assistance due to her increase in debilitating symptoms. As a result, she often feels as though she is a burden on her mother and father. During the interview Karen stated:

> Well as you can tell with my parents they've, my parents are my parents, your loving parents that do things with you and care about you, but my parents have also changed into a new role as a caretaker. Very major roles as a caretaker and I don't want that…it's hard on them and it's hard on me because I know how hard it is on them and it kills me to see how tired they are.

In addition, Karen's role as a friend has changed. While her social support has been narrowed, she continues to value and appreciate the friends she still has. Going into extensive detail when describing the "5-8 club" that she is currently a member of, Karen stated:

> I have some friends from the library where I worked at and we call ourselves the 5-8 girls because a number of us started, well we worked at the library together and we started going out on Wednesday nights…we all went to the same place, it's called the 5-8 grill and bar. So I've got my friends there and they care a great deal about me, a great deal about me, they would do anything for me and I know that.

On the contrary, Karen also discussed what it felt like to lose two of her very close friends as a result of the MS. During the interview she stated:

> Other friends, I lost them. The MS came along with both those people and they just both kind of disappeared out of my life without telling me. And it was at a time that I needed them the most. And I just kept thinking they can't deal with it. So, I lost two of the best friends I ever had. Two of the best friends I think I will ever have.

The idea that life with MS is complicated and requires an individual to make numerous modifications and adaptations was the third theme identified throughout Karen's interview. As can be seen from her previous statements, MS can cause an individual to experience a significant number of debilitating symptoms. As a result, not only has it been necessary for Karen to modify her environment to be safe and functional,

but she has also had to adapt to a decrease in independence and has had to accept help from others to complete her daily activities. During the interview Karen reported:

> I like them there to cook supper for me and then help me get ready for bed and help me get into my pajamas and wash my face, brush my teeth, and you know, all that kind of stuff.

However, while Karen was previously referring to receiving help from personal care assistants (PCAs), due to several complications with various PCA companies, Karen currently does not have help from any PCAs, but instead must depend on her parents. This is an adaptation she has had to make and once again, it has not been easy. She stated:

> So I don't have PCAs at home, which means my mom and dad do more work like you saw today while they were here cooking me supper. They were taking care of the work that needs to be done…they were doing all the PCA work which is really hard, once again, because I want to enjoy their company.

In addition, in order to medically manage her health needs, Karen has had to adapt her schedule and routines in order to be able to fit everything in, possibly sacrificing her free time for medical appointments and treatments. She has also had to plan ahead and set priorities. During the interview Karen stated:

> Fridays are always a, I always have a doctor appointment of some kind. I mean I have my chemotherapy on a, every time I have chemotherapy it's a Friday and all Fridays are reserved for doctor appointments, if possible.

Finally, while MS has had a significant impact on Karen's life, from the physical disabilities to the cognitive and emotional/psychological concerns, she has fortunately been able to find comfort and support through her participation at the MS Achievement Center. While in the beginning she was only attending the center once a week, she has recognized its importance and has adapted her schedule accordingly to be able to attend the center more frequently. Karen summed this up well when she stated:

> So I started going three times a week in June and I liked it so much because it did have a routine for me and I liked it so much because I was with people who understood me. Nobody else understands you like people at the MS Society or Achievement Center do.

Overall, I believe the aforementioned themes and personal quotations accurately reflect the daily life of an individual living with MS and fatigue. While a significant amount of information can be learned through textbooks and academic material, these detailed and rich descriptions of the lived experience of MS can only be understood by actually spending time with those faced with this debilitating disease. These individuals have so much to offer, we just have to take the time to listen.

Conclusions

In conclusion, I am thankful to have been able to participate in this Multiple Sclerosis Fatigue Management Master's Project. Not only did I learn a significant amount about multiple sclerosis and fatigue through the extensive literature review, fatigue management course, and in-depth interview, but I also learned how to be an effective educator when preparing and leading a course to a group of individuals largely impacted by this disease. Each of our participants had a unique story to share and not only did we learn from their shared experiences and insights, but the participants were also able to support and teach one another. Our course sessions were educational, interactive, helpful, and fun, and the participant's appeared to enjoy coming each week. In addition, based on the participant's responses and weekly course evaluations, they appreciated the course information and felt that the program effectively taught them how to take control and better manage their fatigue.

Overall, I believe the wealth of information and experience that I acquired by participating in this project has better prepared me for my future career as an occupational therapist, especially when working with this population of individuals. I look forward to using my knowledge and skills to provide assistance to those in need and hope to return to the MS Achievement Center someday to lead future courses in fatigue management and energy conservation.

Personal Reflections

Leadership Development

I believe the Multiple Sclerosis Fatigue Management Master's Project has had a significant impact on my leadership development. Not only did I gain a significant amount of knowledge and expertise, but I was also given the opportunity to take control and "step up to the plate" when leading a group of individuals in learning about fatigue management. As previously stated, fatigue is a very common and often debilitating symptom of multiple sclerosis, but through proper education, individuals can learn how to better manage this symptom and lead more meaningful, productive lives. Therefore, I felt it was my responsibility to take the initiative, prepare the material, thoroughly learn the information, and plan out each session in order to effectively present the information to those affected by this disease. However, having empathy for and a strong passion to teach these individuals, I found it easier to take an active leadership role. In addition, I have always felt the need and have always wanted to help others, so this project provided me with another opportunity to do so.

On the other hand, while I generally do not have difficulty being a leader and taking an active role, I have come to realize that I do not always demonstrate or feel confident in my ability to do so. I have also realized that I occasionally have difficulty and need to further develop my skills when moderating a group of individuals. I find it challenging to know when and how to appropriately facilitate participation, yet also interrupt individuals during an off-task discussion or activity, as I do not want to be disrespectful or offend anyone. As a result, this periodically affects my ability to be in control and causes me to hesitate more than I should. More specifically, I need to

improve on knowing when and how to appropriately and confidently react to participant responses and actions in order to increase my effectiveness when teaching and leading a group. In addition, if a specific protocol has been set, I often find it difficult to stray from or make my own changes, as I worry that the new result will not be as effective. Therefore, as a future occupational therapy practitioner, I am aware that I need to increase my level of confidence, believe in myself and my abilities, and be more flexible and adaptable. However, I also believe that these qualities and skills will improve with time, practice, patience, and an increased comfort level in the field of occupational therapy.

I have also realized that I appreciate constructive feedback and am able and very willing to adapt my behaviors and actions if I am provided with proper feedback (see Appendix for instructor and peer feedback forms). I believe I am a hard-working and motivated individual who is prepared and eager to make the necessary changes in order to improve my skills and abilities. Overall, I have a strong desire to be successful and help those in need and I believe this is a positive trait to have when taking on a new leadership role as a future health care professional.

Advancement of Occupational Therapy Practice

I believe this Multiple Sclerosis Fatigue Management Master's Project will advance occupational therapy (OT) by providing another area of practice for occupational therapists to specialize in. As can be seen from the literature, MS is a very prevalent and often debilitating disease. Fatigue is also a common symptom of MS, often affecting an individual's life balance, independence, and ability to engage in meaningful occupations. As a result, there is a significant need for occupational therapists to work with this

population. In addition, because our participants reported that the fatigue management course was effective (when taught by future occupational therapy practitioners), these results demonstrate and provide awareness of the benefits of OT practice to individuals with MS and fatigue. Furthermore, this Fatigue Management Master's Project will ultimately impact the MS community by improving the lives of individuals living with this disease.

Relationship to Mission of MAOT Program

The mission of the MAOT program states that it "prepares students to lead and influence occupational therapy practice in existing and emerging professional areas" (OSOT Department, 2008). This Multiple Sclerosis Fatigue Management Master's Project relates to this mission as it provided us the opportunity, as occupational therapy students and future occupational therapy practitioners, to prepare and lead a course in fatigue management to individuals experiencing fatigue as a result of multiple sclerosis. Throughout this course we also focused on the principles of occupational therapy practice. More specifically, we emphasized the importance of taking control and making changes and choices to manage fatigue in order to increase the opportunity to engage in meaningful occupations and live a happy, healthy, more independent, and well-balanced life. In addition and as previously stated, we were able to participate in and significantly contribute to this project, which will advance future occupational therapy practice by positively impacting the MS community. Therefore, as a result, I believe it is safe to say that through our work and dedication to this Master's project, the mission of the MAOT program was accomplished.

References

OSOT Department. (2008). *OT Mission and Curriculum Model.* Retrieved February 26, 2009, from The College of Saint Catherine Web site: http://minerva.stkate.edu/offices/academic/OSOT.nsf